Reproductive Health in Transitional Care: Do Ask, Do Tell
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While most internists are adept at discussing general reproductive health, many are less comfortable when young adults with special health care needs (YASHCN) are involved. The multitude of psychosocial concerns raised by individuals with special health care needs is a daunting challenge for any internist assuming primary care, notwithstanding the disease-specific medical issues. This article broadly addresses psychosocial and medical concerns with regard to reproductive health among YASHCN.

One review article on transition of care suggests that the optimal timing for transition from pediatric to adult providers is after patients can demonstrate comprehension of the following:

- The effect of pregnancy on their own well-being;
- The effect of their medications on fertility;
- Any potential teratogenicity of their medications;
- Genetic risk of their disease recurrence in future offspring; and
- Their own increased susceptibility for sexually transmitted disease.1

The reality is that even among cognitively intact patients with special health care needs, the emotional maturation necessary to comprehend these consequences can be delayed. Parents often vigilantly micromanage their child’s medical care. While this may lead to better medical outcomes, it can impair emotional development and the ability to appreciate potential sequelae of sexual activity.

Interestingly, adolescents (age 16 to 20) with congenital heart disease (CHD) are actually less likely to be sexually active than their healthy peers perhaps due to delays in psychosocial development. Those engaging in sexual behaviors, however, are more likely to be involved in higher-risk activity, including the use of drugs and alcohol prior to sex and unreliable contraceptive use.2 This may be driven by the belief that they are fertile or a lack of information about the risks of sexual activity.

A recent report on the status of new HIV infections in the United States highlights the importance of access to quality transitional care for young adults with HIV. Youths age 13 to 24 currently comprise 25.7% of new HIV cases despite low screening rates;3 72% of these new cases were attributed to male-to-male sexual contact. The psychosocial concerns for patients with behaviorally acquired HIV differ from those infected perinatally. Both groups need counseling about how to disclose their condition to partners and how to prevent transmission. Frank discussion about sexual practices, condom use, and access to barrier protection is of paramount importance to all patients at high risk for sexually transmitted infection (STI) or HIV. Teens and young adults with special health care needs may have difficulty engaging in these difficult discussions.

Complex physical health risks exist among medically ill patients. Pregnancy may be life-threatening in conditions such as advanced cystic fibrosis or severe CHD. Physicians must fully counsel these women regarding the dangers to themselves as well as the risks to the fetus. On the other hand, infertility may be a consequence of some conditions or treatments, especially chemother-apy. Providers must assess this likelihood when assuming care.

Managing medications is a particularly vexing problem for some transitional patients. Patients with autoimmune disease or transplants may not tolerate modifications to their teratogenic medications during pregnancy. Those with cyanotic CHD, right-to-left shunts, and pulmonary vascular disease have increased thromboembolic risk and thus cannot take estrogen.4 Transgendered youth must find adult providers willing to prescribe the hormones necessary to maintain their gender identity. The risk of drug-drug interaction is omnipresent with some anti-seizure and immunosuppressant medications as well.

Additional concerns arise when considering the reproductive health needs of individuals with cognitive impairment. This includes young adults with developmental disabilities like Down syndrome, autism, and countless other genetic, neurologic, or metabolic disorders impacting cognition. Most youth with intellectual disability are mildly impaired with an IQ in the 50 to 75 range. Their interest in sexual activity matches their nondisabled peers, but they may be less aware of how to pursue appropriate relationships. Despite the need for more counseling than cognitively intact peers, they tend to receive less education. The fact that these individuals are often aware of their differences adversely impacts self esteem. This can lead both genders—but particularly young women—to increased

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promiscuity in an attempt to prove normal femininity.

Additionally, parents and caregivers may be fearful about vulnerability to sexual abuse and risks of STI, thus avoiding the topic. Physicians need to provide access to information and specific guidance about what sexual activity may be appropriate. Many medical institutions prioritize the teaching of barrier methods for both cognitively and physically impaired sexually active individuals in order to prevent HIV and STIs as well. Frank discussion about sexual issues and safety is just as vital as it is in healthy adolescents.

Caregivers frequently desire menstrual suppression for young women with more severe developmental delays. Some parents seek to regulate their daughters’ cycles because they note subtle perimenstrual changes in behavior that suggest discomfort, such as increased irritability or poor appetite. No data document improvement in these symptoms by hormonal suppression, but it can alleviate distress created when women cannot understand what is happening to their bodies or the practical concerns related to caregiver burden on hygiene or unintended pregnancy.

Options to achieve decreased menstruation include various delivery systems of progesterone, estrogen/progesterone combinations, or intrauterine devices (IUDs). Permanent surgical treatments are generally not appropriate first-line treatments in young women with mental or physical disabilities.

Depo-medroxyprogesterone acetate (DPMA) is widely used due to its ease of administration and high amenorrhea rates (50% at one year). Furthermore, it does not interact with anti-epileptic drugs or antibiotics and is typically safe when estrogen is contraindicated. Caveats include breakthrough bleeding, weight gain, and bone loss. Some experts suggest titrating DPMA (off-label use) every four to six weeks for three cycles to attain amenorrhea more quickly. Studies in healthy adolescents suggest that thinner women are less prone to the 10 to 20 kg weight gain seen in heavier women. DPMA in adolescents lowers bone mineral density when non-users are still gaining bone mass, but this is at least partially reversible. Problematically, treatment in these patients tends to be longer term, and whether this increases fracture risk is unknown.

Combined oral contraceptive pills (OCPs) can be used for extended cycling, leading to endometrial atrophy and lighter periods. There is a paucity of data on use in developmentally delayed individuals, but breakthrough bleeding patterns appear to be similar to initiation of DMPA. While conventional use calls for quarterly withdrawal bleeds, some experts advocate off-label six- or 12-month cycles, making use more palatable for menstrual suppression.

The transdermal patch can be used to achieve extended cycling and may be easier to administer than other methods. Concerns include decreased efficacy in obese patients and potentially increased thromboembolic risk.

Levonorgestrel secreting IUDs are another option for selected patients. Plasma levels of levonorgestrel are low compared with OCPs, and 44% of women are amenorrheic at one year. There has been reluctance to use this method due to concern for uterine perforation, especially in patients unable to relate abdominal complaints. This is a rare side effect, and use in the developmentally delayed population warrants further study. One downside is that anesthesia is typically required during device placement.

Clearly no single approach works given the diversity of patients who transition to adult care. It is most important to recognize the need for frank discussions about reproductive health and to provide appropriate counselling in this population.

Editor’s Note: The views and opinions of authors expressed herein do not necessarily state or reflect those of Medstar Georgetown University Hospital.

References